

CONVERSATIONS

Carolyn Roy-Bornstein

I am not one of those parents who have been writing about their children since they were born. I was a nurse when my boys were little. I became a doctor when they were six and eight. I didn't have time to write. I barely kept up with their baby books, capturing even fewer cute stories about my second child than I did about my first. Other writers I know who have written about their kids agonized over it. "Do I change their names? Change *mine*? Will they hate me when they're grown?"

I only started writing about my children after my seventeen-year-old was hit by a drunk driver in a crash that killed his girlfriend, Trista, and left him with a serious traumatic brain injury. Even then, it took me five years to get the first word down. At first, it was all I could do to keep putting one foot in front of the other.

Neil spent a week in the intensive-care unit at a major trauma center in Boston, the doctors performing CAT scan after CAT scan, trying to decide if the bleeding in his brain was going to stop or require surgery. He spent months in physical therapy learning to walk on a newly nailed-together leg. He spent years on antidepressants and in therapy, his depression caused as much by his brain injury as by the loss of Trista. What should have been the time of his life—senior year of high school—was one long struggle. My boy, who got a perfect 800 on his math SATs, now needed academic accommodations just to graduate. College was equally disastrous. My once gregarious son now hung back in crowds, his memory loss preventing him from distinguishing between kids whose names he should know from those he'd never met. He lacked confidence. Friends scattered, unsure of how to respond to this new Neil.

While initially it was all I could do to take care of Neil, eventually I felt a deep need to understand what our family had just been through together. And I began to write. Sure, I had journaled all the way through Neil's ordeal. From his bedside, I captured every IV line inserted, every blood draw endured. But it wasn't until five years after the crash that I really let myself explore my feelings on the page. I wrote articles for disability journals sharing our experience of coping with the accident's aftermath. I wrote essays in medical journals about grappling with whether and how to share my family's experience with my patients. I wrote essays for literary anthologies on journaling through sorrow. Finally I wrote and published a full memoir about the trauma our family went through. *Crash: A Mother, a Son, and the Journey from Grief to Gratitude* limned the fine balance between the gratitude I felt because my son survived the crash and the grief I experienced over everything he had lost.

I have never published a word about Neil without him reading it first. I would never be comfortable with my words about him being out in the world if he had not read and approved each one. It became more important to me as the publications became more numerous and had larger circulations. An essay in a medical or rehabilitation journal was only going to be read by medical folks like me. The literary magazines in which my work about Neil first appeared were followed largely by moms. None of Neil's friends were likely to stumble upon any of them. But *The Boston Globe* was a bigger deal. It was critical to me that he knew exactly what I was writing and exactly where each story appeared.

The memoir was different from any of that. There would be a book launch in town. His friends *would* read it. (Or at least their moms would.) So as I wrote, I sent him each chapter and asked for feedback. And he gave it. At first he made minor, less-than-

relevant corrections. “My graduation robe was maroon, Mom, not black.” Or he would make random suggestions on seeming minutiae. “I don’t think you should use the word *tertiary*, Mom. I don’t think most people will know what *tertiary* means.” But that wasn’t what I wanted from him. I wanted to know how it made him feel—how it *would* make him feel if his friends read the book. I wanted to know if I was capturing his experience accurately and if not, where I had gone wrong.

One day, though, Neil gave me more than just feedback on my writing. He told me how he felt. I had e-mailed him a chapter about how now, ten years after the crash, his dad and I sometimes still don’t know what to make of him. By that I mean we sometimes look at him and wonder if what we are seeing—the stony silence, the awkward pause—is a result of his brain injury or if this is just who Neil is now, who he would have become without the trauma.

That night the phone rang. It was Neil, an unusual call, as he’s not much of a phone guy. He got right to the point.

“You know that part in the book where you wonder if it’s the brain injury you’re looking at or if it’s just me?”

“Yes.”

“Well ...”

And here was one of those long pauses that made me wonder. I held my breath.

“... I wonder that sometimes myself.”

I let my breath out. He went on to say that he’s come to understand that it doesn’t really matter how he got here. “It’s just who I am right now.” I don’t know if this was the result of his many years of therapy since the crash or if he had come to this realization himself, but it didn’t matter. He had given me insight into his world. And my book had given us a way to talk about an event that had happened ten years ago, the conversations about it long gone cold.

One day not long ago, he called me up and asked if I could send him copies of his CAT scans and also the results of his neuro-psychological testing.

“Sure, Neil. How come?” I asked.

“I’m petitioning the disabilities office at my school for longer test-taking time and a distraction-free environment.”

At the time, Neil was in graduate school and was in a roommate situation. One of his roommates collected social security, her hip congenitally displaced.

“That’s awesome, Neil. Did you get that idea from talking to Starr?”

“No, Mom. I got it from reading your book.”

Not only was my book helping us all talk about Neil’s brain injury, it was also giving him ideas for how to deal with it. Just as I advocated for him in high school and college ten years prior, now Neil was advocating for himself in graduate school.

Even though I solicited Neil’s feedback when I was writing my book, the first time he read my words was not actually with my permission. One day, a few weeks after he was discharged from the hospital, I came home to find him sitting at the dining room table, a book open in front of him. But it wasn’t just any book. It was my journal. My heart skipped a beat. What had I written there? I racked my brain: Neil pulling off his hospital gown, Neil lashing out at the hospital staff, Neil needing to be restrained.

But before I could decide whether to ask him to stop reading my private entries or let him continue, he looked up at me, his face blank as a plate.

“I’m sorry I yelled at you in the hospital, Mom.”

My heart cracked. Here was my boy apologizing for something totally beyond his control—uninhibited rants caused by his temporal-lobe agitation. He didn’t know he had yelled at me. He

didn't know anything. He was totally amnesic for his entire stay in the ICU. I squeezed his shoulders and pressed my lips to the top of his head.

I knew at that moment that he needed to recover information about those lost days. My journal was filling in his memory for him. He was learning things from the page that I could not bring myself to express out loud: the breadth and depth of my love for him, my deep sorrow at not being able to take away his pain, my guilt at being the mother of the one who survived this terrible accident, my guilt at feeling guilty.

"It's okay, Neil. Read what you want. I'll be here if you have any questions."

But I hovered as he read. I pretended to dust, flipped through books, all the while keeping a wary eye on my son. I worried about what his reaction would be. Embarrassment at his uncharacteristic behavior in the hospital. Anger at me for writing about it. Finally he closed the back cover of the notebook and looked up at me.

"I just like that song," he finally said.

For weeks after the accident, Neil listened to Trista's favorite band, They Might Be Giants, sing a song called "Dead" every morning in the shower. The irony of that song choice was not lost on me. In my journal I had written that I was worried it might be more than coincidence. I worried that it meant he was stuck, obsessing over his lost girlfriend. But here he was reassuring me that this was not the case. Here we were, reassuring each other that it was okay.

Though sometimes in asking Neil's permission to publish, I simply e-mailed him the copy and waited for the okay, at other times, when things were particularly sensitive, I had him read it in person. I had to be sure he actually read each word. In one piece, I wrote about the doctors testing Neil's hearing in the hospital

by rubbing his hairs together in front of his ears and asking him what he heard.

“Beating off,” was Neil’s reply, a helpful reassurance that his hearing was intact but a startling sign that his frontal lobe was not doing its normal filtering job.

When I asked him whether it was okay to share that, he nodded.

I wrote about Trista’s mother, Mary, reading Trista’s diary after she died and finding out that Neil and Trista had had sex.

“If Trista were alive, I’d kill Neil,” she told me. “But since she’s dead, I’m grateful to him for giving her that experience as a woman.”

“Can that stay, Neil?” I asked.

Neil caught his breath and blinked as he read, then looked me right in the eye.

“It can stay,” he said.

Neil came to my book launch party. He mapped out the timing beforehand: when the actual reading would be, the schmoozing, the food. I was not surprised when he was not in the gathering I greeted when I arrived on the scene. I was not surprised when I did not see his face among those seated in chairs listening to the talk. But after the reading, when the crowd dispersed to eat cake and the line formed to have their books signed, there he was: my stalwart support.

That night, Neil took home a few copies of the book for himself. Since then, he has called me up several times requesting additional books.

“Can I have one for Ari?” he’d ask. “I also need one to send to Jeff.”

After the fourth or fifth such request, I began to see a pattern. My book was fulfilling yet another purpose. It was serving as code. As explanation. Neil could hand it to friends who may not have understood what was going on all those years ago. Neil giving

them my book and saying, “This is what my mom wrote,” was also his way of saying, “This is what it was like for me. This is who I am.”

My words have served as many things for our family. In the early days of the accident, my journal was Neil’s memory, filling in the time he missed. It has served as an icebreaker, allowing us to once again talk as a family about something that for so long stayed undiscussed, opening some wounds in the process but ultimately allowing for deeper healing. It served as education, helping Neil to not only recognize his limitations but to advocate for himself to get his needs met. Finally, it has been his shorthand, letting friends more deeply into his world.

There is a lot of talk in memoir about this concept of truth, of telling the truth no matter what the fallout. I always gave Neil total veto power over anything I wrote about him. If he had been uncomfortable with my words, I would not have published them. I wouldn’t have changed things or lied; I just would have kept particular scenes private at his request. Maybe if I had written this book years ago when he was still a teen, he would have objected. But I couldn’t have written it until I did. The writer Graham Greene talks about “the sliver of ice in the heart” of the artist necessary to write about our world. I interpret that to mean that we need temporal distance, rather than detachment, from significant events in order to gain a proper frame of reference to write about them. It’s what I teach my writing students who try to write about their divorces even as they are going through them. And while time gives the writer that needed perspective, perhaps it helps the subject, too. To see things as they are. To balance the *what could have been* with the *what is*. To accept another’s interpretation of the heart.

Carolyn Roy-Bornstein is a pediatrician whose son suffered a traumatic brain injury in 2003. Her 2012 memoir *Crash: A Mother,*

a Son, and the Journey from Grief to Gratitude details the experience from her “other side of the stretcher” perspective. Her nonfiction has appeared in the *The Boston Globe*, *The Writer*, *JAMA*, the *American Medical Writers Association Journal*, and many other venues. Her story “What Halley Heard” won third place in the 2004 Writer’s Digest Short Short Story Competition. Her new book, *Chicken Soup for the Soul, Recovering from Traumatic Brain Injuries: 101 Stories of Hope, Healing, and Hard Work* was released in June 2014.

SKIPPING STONES

Deb Stone

In March 2013, I finished revising *Mother Up: A Memoir*, which is about my transformation from a single mother of twins to an expert foster mom. I understood that my story overlapped with private moments in my family members’ lives. How would they handle that?

For nineteen years, I have been a Court Appointed Special Advocate, a “CASA” designated by the judge to be “the eyes and ears of the court” and “the voice of the child” for children in foster care. I learned that reporting adverse information to the Court without telling the parents in advance caused them to feel blindsided. The more negative the narrative, the more important it was to offer the parents an opportunity to process it privately. As I considered my memoir, I thought, *If this is my commitment to strangers, how could I not do it for the people I love?*

I chose several family members to read the manuscript, not offering to change what I’d written—memoir is not collaboration—but to provide each with an opportunity to read what I’d said